Why Does My Baby Need More Testing for Primary Congenital Hypothyroidism?

State law requires that all babies have the newborn screening test before leaving the hospital. A few drops of blood were taken from your baby's heel and tested for certain diseases. Your baby now needs more testing as soon as possible. Not all babies with an initial "positive" result have hypothyroidism.

California Department of Health Services

Newborn Screening Program
Genetic Disease Branch
www.dhs.ca.gov/gdb

ED3122

Why Does My Baby Need More Testing?

Your baby's test showed a "positive" result for hypothyroidism. More testing is needed to find out if your baby has this disease. Not all babies with an initial "positive" result have this disease.

Babies can look healthy at birth and still have hypothyroidism. If untreated, this disease can cause severe health problems.

What Is Primary Congenital Hypothyroidism?

Hypothyroidism results when the thyroid gland does not produce enough thyroid hormone to meet the body's needs.

Congenital means that the condition is present at birth. If it is not diagnosed and treated within the first few months of life, it can cause severe mental and growth retardation. It can be treated with daily thyroid hormone tablets taken by mouth.

What Causes This Disease?

Babies with hypothyroidism have thyroid glands that are small, located in the wrong place or absent altogether. These glands make small but inadequate amounts of thyroid hormone or none at all.

Is Hypothyroidism Common?

Hypothyroidism is fairly common. About one in every 2,900 babies in California (about 200 babies a year) is born with this disease.

Are There Any Symptoms to Look for?

Parents are often surprised to be notified about the positive thyroid test result because the signs are subtle or hidden in a young infant. The only true, early sign is the high amount of Thyroid Stimulating Hormone (TSH) found by the lab test performed on the newborn screen.

How Is This Disease Treated?

The doctor will prescribe thyroid hormone for the baby. Thyroid hormone, called Thyroxine, comes in tablet form. The baby may require one or more tablets a day. It is important that the baby receives enough hormone every day to grow and develop normally.

If the baby is diagnosed early and treatment is begun early, he or she should develop normally both physically and mentally.

What Happens Now?

The doctor will advise you as to what steps need to be taken. The NBS Program strongly recommends that newborns with positive screening test results be referred to (or their doctor consults with) a California Children's Services (CCS) approved Endocrine Special Care Center (SCC) or CCS paneled pediatric endocrinologist for a diagnostic evaluation including more testing.

Who Will Pay for the Diagnostic Evaluation and Treatment if Needed?

All newborns referred to a CCS-approved Special Care Center (SCC) by the California Newborn Screening Program are eligible for a diagnostic evaluation through the SCC regardless of income. You will be asked to complete an application form to determine eligibility for CCS payment. Most health insurance and health maintenance organizations (HMOs) provide at least some coverage for the diagnostic evaluation and any necessary treatment. If your baby has health insurance, the SCC will bill the health insurance company or HMO for the services. Infants who have Medi-Cal full scope, no share of cost, or Healthy Families subscribers will be authorized by CCS for diagnostic and treatment services and parents will not need to pay anything for services. If you do not have health insurance, or if your insurance only covers partial payment, your infant may be eligible for the CCS program. To learn more about the CCS program visit their website at:

http://www.dhs.ca.gov/pcfh/cms/ccs/.

For a complete list of diseases screened for by the California Newborn Screening Program visit our website at www.dhs.ca.gov/gdb.